Theme 5: Sustainable care at home: understanding the ‘care mix’

5A: Care mix and ageing in place
5B: The evolving nature of the formal care workforce
5C: The role of policy and systems in shaping the care mix
5D: Informal carers within the care mix

Release date: Tuesday 27th April

Theme 5: Sustainable care at home: understanding the ‘care mix’

Session 5A: Care mix and ageing in place

Chair:

Discussant:

Kofi Awuviry-Newton

Using Ethics of Care as the theoretical lens to understand lived experiences of caregivers of older adults in Ghana experiencing functional difficulties

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Caregivers (familial) provide care and support to older adults who experience functional difficulties in Ghana. However, the lived experiences of these caregivers are not well understood. The purpose of this study was to explore and discuss the lived experiences of caregivers using the Ethics of Care as a theoretical lens and Interpretative phenomenological analysis as the methodological approach. Using purposive criterion sampling, ten caregivers in receipt of social welfare services on behalf of older adults were recruited from the Social Welfare Unit at the Komfo Anokye Teaching Hospital (KATH) in southern Ghana. The analysis identified five interrelated themes: 1) committing the Self to caregiving; 2) caregiving impacting the Self; 3) motivating factors to caregiving; 4) caregiving burdens, and 5) thinking about personal affairs. Their experiences demonstrate that caregivers not only value the caregiving relationship, as posited by Ethics of Care but also tend to care for their health and well-being. Caregivers’ expression of commitment to caring for older adults is mainly influenced by reciprocity, despite internal and external stressors, and desire to fulfill unmet personal needs. Ethics of care offers an understanding of the lived experiences of caregivers of older adults in Ghana. The findings draw attention to the state to develop specific programs to ensure the health, social and financial well-being of caregivers of older adults.

Alejandra Marroig

Transitions into dependency with ageing in Europe

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Aging has been related to the onset of dependency in older adults, and Long Term Care (LTC) may be needed to perform daily activities. Some individuals have care needs earlier in life, more urgently or have care needs of greater magnitude. In this project we analysed transitions towards dependency in older adults. We used data (baseline until 2013) from ten countries that participated in the Survey of Health, Ageing and Retirement in Europe (SHARE). We used limitations in Basic Activity of Daily Living (BADL) and Instrumental Activity of Daily Living (IADL) to define dependency states in individuals aged at least 65 years old at study entry (n=20128) and fitted Multi-State Models. We evaluated and compared the association of age and sex on transitions across states and countries, including death. Results show transitions varied with age and individuals had an
increased risk of dependency until 70 years old. International variations were identified. In most countries, women had lower risk of death but higher risk of transitioning into dependency. Sex differences are more pronounced when dependency was defined based on both BADL and IADL. The type of home care distribution at baseline varied by country and sex. Differences in care policies across countries may be underlying these results. Our approach facilitates the early detection of dependency for an aging population and could inform the design of sex-specific prevention strategies and care policies for better quality of life of older adults and their families.

**Mikołaj Zarzycki**

**Exploration of values and motivations to provide care amongst British informal caregiver and care recipient dyads. A qualitative phenomenological study**

**Affiliation:** Bangor University

**Other authors and affiliations:** Val Morrison, Bangor University

The study explores informal caregivers’ and their care recipients’ experience in the context of personal values and their relations to the motivations underlying a caregiver’s role, including investigation of any challenges and any gains perceived by both carers and care recipients.

Care experience was investigated using a combination of methods. Photovoice methodology was adopted at the beginning of the study with dyads being encouraged to take photographs depicting issues they experience either as an informal caregiver or care recipient with an emphasis on their values and motivations for being a carer but also care recipients’ perspective of caregivers’ motivations to provide care. Subsequently, participants were invited to take part in the interviews. Twelve semi-structured interviews were conducted with informal caregivers and care recipients separately and reflective of the photographs each took over a period of two weeks prior to their interview. The transcripts were analysed using an Interpretative Phenomenological Analysis with elements of the Self-Confrontation Method that elaborated the examination of the affective organization of caregiving or care receiving experience. Content management software (NVivo) was employed to streamline the process of coding the transcripts and to critically review the coding rigour applied in analysis of the data.

Values and their relations to motivations to care, any challenges and any gains are discussed highlighting the role personal values and beliefs play in shaping the way informal caregiving and care receiving are manifested and perceived. Different caregiving motives and their implications for caregiver-care recipient dyads are explored.

**Katharina Pelzelmayer**

**A feminist appraisal of ‘caring communities’**

**Affiliation:** Careum School of Health

The notion of caring communities marks a contemporary application of the concept of care. Responding to the ways in which formalised and informal relations of care are expected to face certain moments of “crisis” in the near future, caring communities propagate the re-claiming and re-organisation of care on the local level – the nature of which can be either somewhat autonomous and qualitatively open or led by political communities and/or community networks. The notion suggests that communities both become the social fabric of caring relations and the locus in which (inter)relational care takes place. In countries such as Germany and Switzerland, much attention has been paid to this notion and there have been several attempts to engender and sustain caring communities in rural, peripheral and urban settings. Given that the notion is used in discourses and contexts, which draw little on feminist scholars’ long-standing engagement with care, this contribution offers a critical analysis of the potential of caring communities for feminist endeavours to formulate care in more gender-equitable and sustainable terms. It draws on current participatory research in Switzerland that examines the development of four caring communities with a focus on long-term home care. With reference to this work, I will contrast efforts to build a sustainable culture of interdependent care relations in caring communities to central claims and pillars of feminist scholarship on care. In so doing, I offer a first immanent feminist appraisal of the notion of caring communities.
Release date: Tuesday 27th April

Theme 5: Sustainable care at home: understanding the ‘care mix’

Session 5B: The evolving nature of the formal care workforce

Chair:
Discussant:

Fiona Macdonald

Positioning paid care workers in Australia’s disability support policy: Implications for the ‘care mix’

Affiliation: RMIT University

The recent policy shift to an individualised and marketised disability support system in Australia appears to be reshaping paid care work in multiple ways. However, there has been limited attention given to the treatment of paid care workers within the new disability policy and to the implications of this treatment for care relationships and for the care mix in home settings. This article uses an analysis of discourses in government policy documents and submissions by interested parties to related policy processes to explore the positioning of paid care workers in the representation of the policy problems to be addressed by the new disability support system. The analysis reveals multiple contradictory positionings of paid care workers. It is argued that a significant implication of these various positionings in policy is a blurring of boundaries between formal and informal work. In conclusion it is suggested this has provided a space for government and employers to reduce their accountability for care workers and may lead to a new ‘care mix’ in which low-paid women and immigrants are shifted to the margins of the labour market.

Jo Moriarty

Career progression and a new role to support registered nurses and health care assistants in England

Affiliation: King’s College London

Other authors and affiliations: Ian Kessler, Jill Manthorpe, Jess Harris, Nicole Steils, Kritika Samsi, King’s College London

More than one in ten nursing posts in the National Health Service in England is vacant (Buchan et al, 2019). The introduction of nursing associates as a ‘work-based route into nursing for existing health and care staff or new recruits who may not be able to give up work to study full-time at university’ (GOV.UK, 2017) is intended to address the skills gap between registered nurses and health care assistants. The position of nursing associate can function as a standalone post or be used to progress to become a registered nurse.

This paper will present early results from a study examining the introduction of the nursing associate role in health and social care. Based on early results from analysis of data from stakeholders such as regulators and employers, directors or nursing and nursing associates themselves, it will discuss the pathways by which nursing associates qualified and their experiences in employment. The presentation will focus on intersectionality as a lens through which to explore skill mix in nursing in terms of the extent to which different demographic characteristics, including immigration status and citizenship, shed a light on the nursing workforce.

Jill Manthorpe

Homelessness and dementia in the UK: The interface of housing and care services

Affiliation: King’s College London

Other authors and affiliations: Kritika Samsi, King’s College London; Louise Joly, King’s College London; Maureen Crane, King’s College London; Heather Gage, University of Surrey; Ann Bowling, unaffiliated; Ramin Nilforooshan, Surrey and Borders Partnership Foundation Trust

There are rising numbers of older homeless people worldwide despite the early risk of death of being homeless. Provision for older homeless people varies but much of it is based in hostels that are run by third sector or private companies. The numbers of older homeless people with cognitive impairment or dementia are unknown and little is known about their care.

This presentation is based on selected findings from the first study of older homeless people with possible memory impairment or dementia in the UK. Based on findings from a sample of eight hostels, 44 staff were interviewed and hostel and medical records accessed for participating residents. Memory assessments were undertaken to ascertain if residents showed signs of memory impairment. Most older residents interviewed had complicated background histories, including learning difficulties, incomplete education, long-term alcohol misuse and physical health conditions, including brain injury. The study revealed that hostel staff were undertaking a variety of care and support tasks for residents with memory impairments including care tasks and help with activities of daily living; some residents were receiving home care services after local authority assessment of their needs. Difficulties were reported by residents and staff of moving on from hostel to more appropriate accommodation such as care homes and the limited options available. There were also challenges in inter-agency
working and referral routes. The study has provided new evidence of the interface of housing and care services relevant to growing numbers of the population.
### Theme 5: Sustainable care at home: understanding the ‘care mix’

#### Session 5C: The role of policy and systems in shaping the care mix

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**Annie Dussuet**  
**Constructing the division between declared paid and unpaid caregivers. A street level analysis of public agents implementing the French “Personalized Allowance for Autonomy” (APA)**

**Affiliation:** Université de Nantes  
**Co-authors and affiliations:** Clémence LEDOUX - Université de Nantes

In France, care for the elderly is mainly financed by the “Personalized Allowance for Autonomy” (APA), which can be taken at home or in nursing homes. This allowance is defined nationally by law, but implemented locally by the different départements. When distributed at home, a “help plan” is established for the eligible persons, it describes the services which have to be distributed and the level of the financial support from the département. This help plan is drawn up by the département’s agents after having read a medical and a family questionnaire and visited the homes of the applicants.

An important question remains: how do these practices contribute to determine the care mix? In particular, how is the division of work constructed, between paid care service providers, directly employed people and those who, in the entourage of elderly people (family, friends or neighbors) are not recognized institutionally as care providers and work unpaid or undeclared, but whose research has showed the essential character?

Based on a qualitative research carried out among 35 agents of a French department, this paper will show the role of the implementation of French public policies in organizing a divide between declared paid and unpaid work. We will see in particular how the care work is denied, in favour of what is seen as “natural solidarity” towards the elderly, and the consequences of this approach, especially in terms of working conditions for paid caregivers (fragmentation of work and invisibility of skills), and gender inequality reproduction.

**Takuro Higuchi**  
**Post-Independent Living Movement under Neo-liberal Welfare Reform in Japan**

**Affiliation:** Tokyo University of Foreign Studies

In Japan, the turning-point of the Independent Living movement of the people with disabilities has been recognized in recent years. Different researchers identify different viewpoints for the turning-point, such as, 1) the goal of the movement got acquired in some points, 2) the policy target of IL was expanded to those who formerly conceived of impossible to live independently, and 3) the reform of welfare regime in response to neo-liberalism. This paper aims to describe an underlying element of the turning-point recognized.

An essential argument was proposed by Nancy Fraser, which asserted that the second wave of feminism intending the independence of the women had a secret affinity for neo-liberalism. After that, following analysis on complicity between neo-liberalism and the welfare policy supporting to be independent have been accumulated since 2000s.

Significant welfare reform begun in 1997 in Japan, then many of welfare policies supporting to be independent had been enacted. Primary policy targets were the women, the poor, the homeless and the people with disabilities. Some analysis were conducted on those categories of people in Japanese context, however, the analysis on the people with disabilities is lacking.

This paper investigates the complicity between neo-liberalism and Independent Living Movement especially after the reform of Japanese welfare regime.

It is shown that the evaluation of welfare policies supporting to be independent is divided and paradoxical. The IL movement had also developed paradoxically, and it can be one of the reasons why the turning-point of the movement is recognized in 2010s.

**Shereen Hussein**  
**Migrant care workers in the ‘care mix’: The experience from five countries with diverse care and migration regimes, and lessons for a post-Brexit UK immigration system**

**Affiliation:** London School of Hygiene and Tropical Medicine  
**Other authors and affiliations:** Agnes Turnpenny (PSSRU, University of Kent), Sara Charlesworth (RMIT University)
Migrant care workers provide an important contribution to the provision of care for older and/or disabled people in many countries. Their share, composition, and roles are largely determined by the intersections of care, migration, and employment regimes (Williams, 2012) and intertwined with migrant agency (Christensen, Hussein, & Ismail, 2017).

Sectoral and low-wage visa programmes are recognised to be challenging from a policy design and implementation perspective, and in the case of social care this is further amplified by high levels of fragmentation and segmentation within the sector.

This paper maps and compares migration regimes in five countries (Canada, Australia, Taiwan, Japan, and Singapore) with diverse care and migration arrangements. Four aspects of legal status will be considered that have been highlighted as important in shaping the living and working conditions of migrant care workers (Cohen-Mansfield, Garms-Homolová, & Bentwich 2013). These include 1) opportunities and challenges of visa schemes allowing free access to the labour market for certain groups of migrants; 2) the availability of and conditions for temporary or sector-specific work visa programmes; 3) access to settlement and naturalisation in the host country, and 4) regularisation programmes for undocumented migrants/workers. The paper will review and discuss available evidence in relation to the impact and outcomes of these arrangements with a view to inform debate around potential UK post-Brexit immigration systems, in relation to the care sector.

Salla Era

Disability and old age in the upcoming disability legislation reform in Finland

Affiliation: University of Jyväskylä

Relating to my doctoral dissertation, this paper focuses on the discussion around age-related restriction in the disability legislation reform in Finland. The main aim of the upcoming reform is to merge two existing Acts regarding persons with disabilities: the Disability Services Act (380/1987) and the Act on Intellectual Disabilities (519/1977). In addition, contents and coverage of the Act will be revised. Even though the prevalence of disability is higher in older populations, older persons tend to be excluded from disability discourses. In the six largest cities in Finland, 61% of persons receiving disability services were over 65 years old in 2018. In the revision process, it was debated whether older persons should be excluded from the disability services, either by setting a categorical age limit or excluding persons with age-related disabilities. In this research, I analyse public statements given in 2017 to a proposal that introduced an age-related restriction to disability services. I focus on how the restriction is argued for and against, and how these arguments are justified. This study suggests that although the arguments differ on each side, the main principles remain the same: equality and justice, as well as efficiency and legality, are used on both sides. Thus, both the opposing and supporting arguments can be justified with the same kind of principles. This makes it nearly impossible to draft an indisputable argument for either side. The crux of the issue seems to lie in varied understandings of disability, old age and therefore, equality and justice.
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**Theme 5: Sustainable care at home: understanding the ‘care mix’**

**Session 5D: Informal carers within the care mix**

**Chair:**

**Discussant:**

**Petra Ulmanen**

**Realization of ageing in place policy in Swedish eldercare: consequences for family members as informal carers**

**Affiliation:** Department of Social Work, Stockholm University

From being an empowering policy enabling older persons with care needs to continue living at home without becoming totally dependent of their families; today the Swedish ageing in place-policy has the opposite effect, it limits choice and increases family dependence. The de-institutionalisation trend has been more dramatic in Sweden than elsewhere, resulting in increasing numbers of older persons with extensive needs being cared for at home. The residential care decline has however not been compensated by increased home care, in particular not regarding the intensity of care. Furthermore, home care workers’ capacity to meet their clients’ needs has declined, as increased standardisation and fragmentation of home care work have caused staff discontinuity and limited job discretion. As care services have become less available and more fragmented, the need for family members to provide managerial care in particular increases (i.e. handling contacts with care services, including getting access to and coordinate services). Based on a longitudinal interview study with 55 family members of older persons with extensive health and social care needs, the paper aims to answer the following questions: 1. How do these family members perceive the ability of care services to meet their parent’s/partner’s needs? 2. How do they perceive providing managerial care? 3. How do these phenomena affect their lives? Conclusion: The realization of ageing in place-policy in Swedish eldercare has high costs, regarding the well-being of frail older persons, as well as the well-being and labour force participation of middle-aged women, which also threaten financing of services.

**Masa Filipovic**

**Family and welfare state: care decisions within user-family carer dyads in life course perspective in Austria and Slovenia**

**Affiliation:** European centre for social welfare policy and research

Other authors and affiliations: Ricardo Rodrigues, European centre for social welfare policy and research; Selma Kadi, European Centre for Social welfare policy and research; Masa Filipovic Hrast, European Centre for Social welfare policy and research; Valentina Hlebec, University of Ljubljana, Faculty of Social Sciences

When considering the distribution of care between formal and informal carers, empirical studies have identified a number of factors impacting this care mix. Very seldom however, do studies consider the choice of care-mix as the result of life course process. This study aims to fill this gap by shedding light on the factors leading to the choice of care mix within a heterogeneous group of families. To this end, it uses qualitative data collected through semi-structured interviews with dyads (older users of home care using formal and informal care and their adult children providing informal care) carried out in Austria and Slovenia in 2019. The sample includes a total of 75 dyads (150 interviews), purposely selected to reflect diversity of sex and social class. Employing framework analysis, this study provides an in-depth investigation of the life course events leading to the provision of care. It focuses on the possible role of linked life events (within wider family), specific transitions (related to work, living arrangements etc.), reciprocity within the family and individual (previous) experience with care. Data is analysed both with an intra and intercountry focus. Within each country, it compares decisions along gender and social class lines. Between countries, it explores the impact of each country’s ‘care culture’ and public policies, the latter analysed through the lens of different degrees of familialism (supported vs familialism by default).

**Norah Keating**

**Care workers and family carers: Constructing the evidence of challenges to sustainability of the care labour force**

**Affiliation:** Swansea University

Other authors and affiliations: Maria Cheshire Allen Swansea University; Sue Yeandle Sheffield University

The importance of providing timely, responsive and person-centred care to frail older persons is a key theme in contemporary discourses about the challenges of population ageing. Yet there is a widening ‘care gap’, in which fiscal and human resources are seen as inadequate to meet rising care needs. In this presentation we turn to the human-resource element of the care gap: family carers and care workers. We argue that in the relentless search for more care capacity, we risk further eroding the already fragile resources of carers.

In this presentation, we review extant research on consequences of care to family carers and to care workers. We find ample evidence of poor working conditions of care workers including long hours, low wages, lack of benefits, tenuous job security. Relational issues of disrespect and discrimination are pervasive across work settings. The work of family carers is similar but
largely unpaid and invisible. There is growing evidence of negative impact on their social connections, financial status and health. Based on these findings, we propose a set of criteria for decent work and for enhancing relevant relationships, setting these within a discussion of wellbeing of those who provide care.

**Ana Ramovš**

*Women and caregiving in Slovenia: Their role and experience of informal care*

Affiliation: Anton Trstenjak Institute of Gerontology and Intergenerational Relations

Other authors and affiliations: Jože Ramovš & Ajda Svetelšek, Anton Trstenjak Institute of Gerontology and Intergenerational Relations

While all over the world women are still the predominant providers of informal care, with the change of traditional patterns and raising number of women entering the labour market, their role is becoming more and more controversial around the Europe and North America. Many studies which have examined gender differences among informal carers, have reported that women experience greater physical, mental and financial strain, greater caregiver burden and are more likely to drop out of the labour marked. At the same time, there is almost an equal number of studies that have not found any differences between men and women on most of these aspects. Be that as it may, it is indisputable that while there are many papers focusing on the negative impact of caregiving on woman there are very few papers exploring the value of the informal care provided by women. Our presentation aims to present part of this value from the woman’s point of view, taking into account Slovenian cultural and anthropological context.